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Perspectives on Eating Disorders and Service Provision: A Qualitative Study of
Healthcare Professionals

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Perspectives on Eating Disorders and Service Provision: A Qualitative Study of Healthcare Professionals

Abstract

The study examined healthcare professionals' perspectives of eating disorder patients and services. Qualitative semi-structured interviews were conducted with 18 healthcare professionals resulting in two themes. First, the practical difficulties of meeting the complex service needs of people with eating disorders were illustrated. Second, staff recognised patient diversity and the consequent need for individualised interventions. Services are frustrated in meeting patient needs due to complex resource limitations, which do not amount only to lack of funding. Rather than eating disordered patients being viewed as 'difficult', as reported in previous qualitative research, they are only difficult in a context of limited resources.

Key Words

Healthcare professionals' perspectives, eating disorders, specialist services, qualitative, service evaluation.

Perspectives on Eating Disorders and Service Provision: A Qualitative Study of Healthcare Professionals

Eating disorders such as anorexia nervosa and bulimia nervosa are serious because sufferers often present with severe physical and mental health complications (Comerci & Greydanus, 1997; Katzman, 2005). The standard mortality rates are 1.6 for bulimia nervosa (Nielsen, 2003) and 10.5 for anorexia nervosa (Birmingham, Su, Hlynsky, Goldner & Gao, 2005), giving eating disorders the highest mortality rates of any mental health diagnosis. There is also epidemiological evidence that eating disorders are increasing (Van Hoeken, Seidell, Hoek, 2005). It is therefore imperative that patients receive effective treatment by experienced and competent staff (NICE, 2004).

There are many issues around lack of training for healthcare professionals and scarcity of services for eating disorders (EDA, 2000, 2005; Jones & Lerner, 2004; King & Turner, 2000; Lemouchoux, Millar, & Naji, 2001; Ramjan, 2004; Royal College of Psychiatrists, 2000; Wall, 2004). Specifically, a report published by the Royal College of Psychiatrists (2000) found that only 33% of health services in the UK had specialist eating disorder services and “*spending on eating disorders is grossly inadequate*” (p.16). Service staff are receiving insufficient training in eating disorders (Wall, 2004) leading to a lack of competency and confidence when working with this patient group (Jones & Lerner, 2004).

Clinical guidelines for eating disorders set out by the National Institute for Clinical Excellence (NICE, 2004) prioritises the requirement that services be competent in giving treatment and assessing the physical risk of people with eating disorders. It

also recommends that the treatment, by appropriately skilled professionals, include specific forms of psychosocial intervention alongside appropriate management of the physical consequences of eating disorders.

Effective therapeutic relationships are important for the successful treatment of eating disorder patients (Comerci & Greydanus, 1997; Kaplan & Garfinkel, 1999; Muscari, 1988). However, this can be impeded by non-compliant behaviour and consequent professional mistrust (Hepworth, 1999; King & Turner, 2000; Ramjan, 2004) resulting in the view that eating disorder patients can be considered difficult to treat (Kaplan & Garfinkel, 1999; King & Turner, 2000) and resistant to treatment (Hepworth, 1999).

Qualitative studies enable researchers to explore the issues and experiences of importance to those being interviewed rather than exploring pre-determined constructs decided by the research team. Although there are well-known ethical, practical and systemic problems treating people with eating disorders, there remain few qualitative studies of healthcare professionals' attitudes and experiences of eating disorders and their treatment. Previous qualitative studies have focussed specifically on the eating disorder, the patient or the therapeutic relationship (Hepworth, 1999; Jarman et al., 1997; King & Turner, 2000; Ramjan, 2004; Ryan Malson, Clarke, Anderson & Kohn, 2006). Yet, there are wider issues that affect how eating disorders are treated, so this study set out to explore healthcare professionals' views of eating disorders and the services provided for them. The purpose of this study was therefore to identify service staff perspectives and experiences of providing services to those with eating disorders.

Research design and methods

Setting

The study occurred in a large Northern city in the UK. At the time of the research, for people with eating disorders the city had a small National Health Service (NHS) outpatient eating disorder service, beds in a NHS hospital general medical ward and a privately funded residential service. All three settings were contacted for participation in order to explore the range of service options available to patients. By covering all services the research should have greater opportunity to explore both the successful and unsuccessful aspects of providing care for this patient group. Given the small and specialised nature of eating disorders in this locality, participants were generally aware of the basic nature and functioning of all the services.

NHS patients included only people with anorexia nervosa and bulimia nervosa, other eating problems being ineligible. The outpatient service was staffed as described below. NHS patients requiring inpatient care were referred either to the NHS hospital general ward, or to the private service. The private service predominantly treated anorexia nervosa. It was the only inpatient specialist service in the area, so it took private referrals directly from primary care and local GPs. The private service also took self-referrals, which included some people who had self-diagnosed, but had no formal eating disorder diagnosis. Bulimia nervosa sometimes develops after a history of anorexia nervosa (NICE, 2004), which means that in the life course the two disorders are not always distinct. Therefore, it was decided to ask about 'eating disorders' rather than separately about the different diagnostic classifications.

Participants

Eighteen participants were interviewed, which comprised all the staff specialising regularly with eating disorders in the study city; nobody refused to participate. Nine worked solely within the NHS. All five permanent staff in the outpatient service were interviewed: A psychiatrist, a psychologist, a community occupational therapist (OT; who helps patients adapt to their physical or mental health problems to gain more independence and control), a general practitioner (GP) on a psychiatric placement and the outpatient project leader, who was also an OT. In the UK, OTs not uncommonly play a role in eating disorders treatment. The four main senior general ward staff involved in eating disorder treatment were interviewed: A dietician, a dietician manager, an F grade sister (the senior nurse responsible for the day-to-day management of the ward) and a consultant endocrinologist. All seven available private service staff were interviewed (this did not include less permanent, other sessional and support staff), including a consultant psychiatrist, a matron (equivalent of the NHS F grade nursing role described above), two registered mental health nurses (RMN), an art therapist (providing psychotherapy through art) and two support workers. Support workers may not be professionally qualified, but provide support to health care professionals and can spend a lot of time with patients, providing emotional and practical support. An additional two worked in the private service and the NHS: Another RMN in the private service was also a medical student and another support worker worked in both environments. This sampling represents all the types of personnel working with eating disordered patients in the study area, and includes all the senior staff involved in the services. Because several of the staff were unique in terms of their profession and role, and results did not differ systematically according

to professional background or experience, participants are only identified by their place of employment and an arbitrary ID number.

Procedure

The research was approved by the Local NHS Research Ethics Committee. Potential respondents were recruited through their managers who agreed to pass on the written information about the study and the invitation to participate. Potential participants who agreed to take part were then contacted by the researcher and consent to take part was signed, nobody refused to participate. Semi-structured interviews were conducted in a private room at their place of work, at the respondent's convenience. Respondents were asked about their training and background regarding eating disorders, their opinions about treating people with eating disorders and their views on the eating disorder service they worked for. All interviews were, with each participant's consent, tape-recorded and later transcribed verbatim. The researcher conducting the interviews was based at the local university and independent of the services. It was hoped that this would promote candour and increase the likelihood of open reporting, but participants often found the topics difficult to discuss nonetheless.

Data Analysis

An inductive, semantic approach to thematic analysis was used to analyse the data, using the six phase process outlined by Braun & Clarke (2006). Data was analysed by the second author, a qualitative researcher with experience in researching eating disorders, who then discussed themes with the other two authors. The final analysis was later reviewed in depth by the first author who was also familiar with the transcripts and who has clinical experience in working with eating disorder patients.

The first step involved the researcher becoming familiar with the data by re-reading the whole data set and making notes of early relevant ideas. Second, initial codes were generated by identifying and labelling particular features and concepts within the data that were important. The third stage involved collating all relevant codes together into overarching themes. These themes were then reviewed, in stage four, to ensure that they worked with the original transcripts and to ensure consistency in interpretation between the three researchers. Stage five consisted of defining themes with a label that clearly indicated the content of that theme. The final phase outlined by Braun and Clarke (2006) consists of the write-up of the results which involves piecing the themes together in an “analytic narrative” (Braun & Clarke, 2006, p.93).

Results

Participants’ descriptions centred on two overarching themes. The first theme involved a complex of practical issues in the management of eating disorders, which participants felt led to patient needs being inadequately met. This theme was dominant in participants’ narratives and therefore makes up the greater proportion of the results. Interrelated practical issues included lack of training and skills, the appropriate setting for treatment, increased demand for services, challenges of allocating scarce resources; including funding problems, what referral pathways were appropriate and (in the NHS) how staff shortages impacted treatment. The second theme concerned the diversity of patients with eating disorders in terms of etiology and appropriate treatment. As will be seen, these two themes interrelate whereby the diversity of patients’ needs were considered difficult to meet given the practical issues involved in managing eating disorders.

Theme 1 - Unmet needs: Practical issues in the management of eating disorders

Participants in both the NHS and private setting spoke about their concerns that patients' needs were not being adequately met for a number of reasons. Services were inundated with too many referrals but not enough time or resources to adequately manage patients' care and as a result some staff felt they should refer patients on but as this participant states: *"it's not answering the problem, it's moving it on"* (P12, private setting). However, the outpatient service felt they should treat patients as best as they could, despite this being insufficient: *"We don't, at the moment, turn people away, even though we can't adequately satisfy the needs"* (P1, NHS outpatient services). This therefore has important implications on the treatment that patients would receive and raises some important questions. For example, is some kind of treatment better than no treatment at all? Or can this less than adequate service be detrimental to the patient's health?

Training and skills

Although a more prominent problem in the NHS, participants from all settings described a lack of training or understanding about eating disorders. Many were employed with no relevant training or experience beforehand and were expected to pick up knowledge as they went along. The 'training' that participants did receive included attending conferences, study days or short training courses. Participants felt that this level of training was inadequate especially as they did not receive enough support or funding to further their knowledge and understanding of eating disorders.

As these participants describe:

Right, as an [...], training was done on the hoof, it's basically as you come across it you scrabble around for support and information that makes sense. (P17, private setting)

I am wanting to do more training and I'm wanting to go on the course for eating disorders but the problem is with it being a private clinic is getting the funding together. (P13, private setting)

Participants recognised that eating disorders were a specialist area and thus their training needed to reflect this, yet many did not feel they had the right amount of specialist knowledge. Healthcare professionals believed that a higher level of training was necessary for those dealing with this patient group and many wanted this further training especially as they had an interest in the area of eating disorders. As a result, some participants supplemented their 'on the hoof' training with their own research out of work: *"Since I took a particular interest I suppose I've attended to my own training by reading, attending conferences, and practising and visiting other services of excellence"* (P1, NHS outpatient service). The lack of training caused some staff to feel unable to help patients resulting in feelings of frustration. As the next quote describes, this frustration can impede the therapeutic relationship making effective treatment even more difficult:

I think a lot of the staff genuinely do care and they perceive themselves as trying to do a good job and criticism of that or their frustration because they are not using the right tools or approaches makes them more entrenched and actually increases frustration and sometimes colours their perceptions and their relationships with the residents (P17 private setting).

Treatment setting

Related to this, the treatment setting will also have an impact on the level of skills a member of staff would have in managing eating disorder patients. Those participants who had worked in (or were currently working in) NHS ward-based settings believed that this was not the right environment for those being treated for an eating disorder due to a lack of the specialist expertise needed for treating eating disorders. For example, *"A ward environment, to me, isn't the right environment for people coming*

into hospital. The nursing staff don't have the training to cope with people with anorexia either" (P7, NHS medical ward). The percentage of ward-based patients admitted with an eating disorder is relatively low which means that general medical staff do not have regular contact with eating disorder patients and therefore may not be as efficient in treating them as staff within a specialist environment. Similarly, although medical ward staff provide support they are unable to offer the psychological care that patients need: *"it's not expert support in psychological and behavioural needs [...] because we haven't got the knowledge and the background to do that"*. (P8, NHS medical ward)

The ward setting was also considered inappropriate due to the level of care, in terms of time and supervision needed for this patient group. Thus, participants believed that a specialist eating disorder clinic, focused only on providing care for this patient group would be able to provide the time and level of care that those with an eating disorder require:

And, you know, it can be quite difficult to find a lot of time for one patient when one might well have many other patients to deal and busy clinics to do. (P9, NHS medical ward)

The increasing need for appropriate services

Participants recognised an increasing need for appropriate eating disorder services due to a larger number of people presenting with an eating disorder than they had previously, as this dietician manager describes:

I think the numbers have increased over the years. When I first came to [City] six years ago and in terms of the inpatient side we might have one every now and then. It wasn't any great numbers. And then maybe, about two years ago we were finding we always had somebody on the ward. (P7, NHS medical ward)

However, at the same time they were worried that this number was only a representation of a much larger population. Related to this, respondents also recognised how eating disorders span a much wider problem than the extreme cases that they were able to deal with within the services. The art therapist of the private service discussed how although the service only saw a “small proportion” many people with eating disorders may go undiagnosed and remain hidden:

In terms of numbers [...] I really don't know, because I think a lot of eating disorders are hidden. I think a lot of people have eating disorders that are undiagnosed [...] But in terms of the number of patients of services I think a small proportion of the people might have eating disorders. (P14, Private setting)

Funding Issues

Although a number of respondents in the study recognised the growing need for eating disorder services, they felt this was not true for the funding authorities. Respondents in the NHS settings discussed financial barriers to the services they provided by describing how practical demands on the funding of such services meant that they were under-resourced. This had a noticeable impact on the services that they could provide for patients that again related to an inability to meet patients' needs, as P1 (NHS outpatient service) expresses, *“the further limitations are the health provision planning environment where it's difficult to move resources around to every obvious areas of need.”*

Differences between the NHS and private services were apparent when it came to funding. Private services rely on the funding of their patients whereas NHS services receive their funding from health authorities. Both types of setting depend on this

funding for the effective running of the service. The level of funding determines the amount and types of staff the service can employ, the level of training staff members can receive, the types of service they can offer their patients and the number of admissions the service can take on. Having to pay for treatment can also be problematic for patients who sometimes may not receive enough funding to meet their needs, this may cause anxiety for patients who may require more treatment. *“I think that one of the problems is when the funding runs out, not getting enough backup after that. [...] It worries the patients quite a lot”* (P16, private setting). Thus, it seems patients have a choice of using NHS services that may be under-resourced and unable to adequately meet their needs or risk finding funding for private services that may end before they have received the full course of treatment.

Staffing levels

Staffing levels differed amongst the two types of service, whereas both NHS services were severely understaffed and overstretched, the private services had a high staff-patient ratio. Higher staffing levels means that there is a greater mix of skills within the staff members, more time can be spent with patients and the service can more readily meet individual needs. The consequences of low levels of staffing within the NHS mean patient's needs cannot be adequately catered for; staff cannot cope with some patients, they are turning people away and cannot spend efficient time with their patients:

the problem now is that the staffing is totally inadequate to meet the need [...] the next step in my opinion is to increase the staffing and also to put ourselves in a position where we can cater for people with more complex difficulties (P5, NHS outpatient service).

Referral

Referral criteria between the services varied and this can be linked with the staffing levels. The NHS services had to prioritise patients who were more severely affected by their eating disorder or who were considered more motivated to accept treatment. The NHS could only take patients with anorexia nervosa or bulimia nervosa; they could not accept people with binge eating disorder or with their eating disorder as a symptom of another disorder. The private service also did not take those with an eating disorder as a secondary symptom but apart from that the only other restriction was whether the patient has sufficient funding:

We don't really have any guidelines on who we take. We take people who usually have been diagnosed with an eating disorder although we have had referrals from patients who haven't actually formally been diagnosed with an eating disorder but do have eating problems. And we don't just deal with anorexia and bulimia, we deal with obesity and compulsive eating as well as the sort of obsessional type behaviours that come along with that (P13, private setting).

Overview of services

Participants from both types of services felt that the services were good but they also agreed that further improvements could be made. The main areas for improvement in both settings were for the service to expand and offer more types of treatment. A number of participants agreed that services in the area should work together. As one manager described it, there was a particular need to:

Link up all these pieces, what's at the NHS service, what's in the private sector with the acute side as well. And I think that's to me what's missing is that it should be managed as a service not as chunks in different trusts in different organisations (P7, NHS medical ward).

Theme 2- "Everybody is different": The nature of eating disorders

Most participants believed that a number of different causes were responsible for the onset of an eating disorder where patient will experience a number of precipitating experiences and for each person these experiences will be different. As one participant stated: *"I don't see it as having one particular cause"* (P12, private setting). Two of the most commonly described precipitating or predisposing factors for eating disorders were family issues and low self-esteem. Other factors included pressures on the individual, control issues and abuse. Staff thus believed that treatment needs to be tailored accordingly to meet individual needs through a personal treatment plan that focused on the person rather than their diagnosis. Participants expressed how some treatment interventions or treatment services would not be right for everybody as a result of their individual needs:

You have to treat the individual really and what works best for them rather than saying we will adopt this approach or we will adopt this approach (P13, private setting).

Participants therefore believed that the holistic approach of addressing all aspects of the person (psychological, physical and social) was imperative. In particular, many recognised the importance of addressing patients' psychological issues. This included developing new coping strategies, changing attitudes and behaviours and dealing with underlying problems and the reasons behind the eating disorder, as this psychiatrist expressed when describing the important aspects of care:

I think it's to establish a therapeutic relationship [...] To not seek to take control away from the individual, rather to empower them [...] to help them to develop new coping strategies so that in time they can give up using pathological control of diet, weight, exercise (P1, NHS outpatient service).

Other staff felt that the most important factors in treating eating disorder patients included having a multi-disciplinary team and a trusting therapeutic relationship,

which involved listening to the patients and providing support and this therapeutic relationship went hand in hand with having the right treatment environment:

I think you need sort of an atmosphere where patients feel safe and feel that they can trust the people that they're working with [...] we try and make it as homely here as we can (P13, private setting).

Eating disorder patients as "difficult"

Perhaps because of the highly individual nature of eating disorders, patients were thought to be a difficult patient group. They require high intensity of care which means high levels of treatment, high demand on staff members' time and high levels of input from staff. This was expressed as:

I think we would say that one of the problems we come across is that patients often demand a lot of time [...] No two patients are the same but certainly some of them have been very demanding and that has been quite difficult (P9, NHS medical ward).

Part of the difficult nature of caring for eating disorder patients was their lack of motivation for treatment and subsequent non-compliance. As found in previous research (e.g. Hepworth, 1999) this could lead to staff to form unhelpful and unfavourable views of their patients. Importantly though, as the following quotes illustrate, these views were recognised as unbeneficial and in need of changing if successful treatment is to be provided:

It's an area of mental health I think that is quite refractory to treatment. It seems manipulative, people are described as 'Manipulative and devious', 'They're not motivated' is another phrase 'Until they want to have help then there is nothing I can do' and to be quite honest it pisses me off when people say that. I think it's a cop out. (P17, private setting)

Discussion

This study broadened qualitative inquiry about health care professionals' views of eating disorders to encompass service provision as well as the nature of the disorders and the therapeutic relationship. Participants did find eating disorder patients difficult and often felt frustrated that they struggled to meet their needs. However, this 'difficulty' was not only due to the intrinsic complexity of eating disorders as psychological problems, which can include non-compliant and devious behaviours to avoid eating or gaining weight. Difficulties were also attributed to the complexities of providing appropriate eating disorder services. Indeed, in practitioners' discourse the practical difficulties of service provision received more attention than the difficulties of working with eating disordered patients. As these participants understood it, the 'difficulty' of eating disorder patients was a systemic problem to do with a complex interaction between patient characteristics, staff training and competence and service resources. Many recognised that patients with enduring and complex needs deserved better treatment than could be provided. Previous research has tended to locate 'difficulty' either in the eating disorder patient, or in the health care professionals' lack of appropriate training.

Participants seemed to have a collective vision of the ideal service where people with eating disorders would receive protracted and individualised treatment with a substantial psychological component from highly trained and skilled healthcare professionals. They were frustrated that this was not always possible and identified a number of practical barriers that they felt reduced quality of care. These shall be discussed in a logical order starting with pathways into care.

Participants had noticed an increase in service use and suspected that there were many people with eating disorders in the community who never engaged with services. They did not feel that the three services in the City (private residential, specialist NHS outpatient, general NHS medical ward) constituted a coherent or well-planned whole (although at that time this level of provision was higher than in some other parts of the UK). A limitation of the study is that there was no specialist residential NHS eating disorders service in the city studied. Participants felt that eating disorders were shifting from being perceived to be rare disorders usually dealt with by general psychiatric or medical services, to being common disorders requiring dedicated resources. There were challenges managing this transition.

There were only a limited number of places in the services and sometimes people were referred on the basis of availability rather than individual need. This raised the question of whether any treatment is better than none? This may be so during a crisis, such as being life-threateningly underweight. However, participants identified risks of patients receiving inappropriate treatment, including being tied into a private treatment regime that they could not afford to complete, or being discharged from the NHS when the crisis had subsided to make way for others, but before treatment was complete. Better planning and collaboration across the services might have helped. Such planning would ideally include a sensible care pathway, so that treatment neither ceased prematurely, nor continued inappropriately in residential settings because insufficient community-based places were available.

As in previous research, staff found patients with eating disorders challenging to treat. They recognised that they had complex treatment needs and that change was often a

protracted process, which some staff did not feel fully competent to manage. This led to frustration. As in previous research (Jones & Lerner, 2004; Royal College of Psychiatrists, 2000; Wall, 2004) staff believed that if they were better trained, and if more, better-trained staff were available, treatment would be better. This endorses the need for better training and continuing professional development on eating disorders (NICE, 2004). However, NICE (2004) guidelines also identify the need for better treatment of eating disorders in primary care. In an area with well-planned services, this might include better initial recognition of eating disorders and better long-term monitoring and support for people who had received specialist treatment.

Implicit in staff views of a skills gap hindering treatment is a model of a specialist practitioner doing skilful things to treat a complex case; a paternalistic model of health care, which has a particularly bad fit with eating disorders. As laid out in cognitive behavioural therapy (Cooper, 2005), patients need to take active control over their own thoughts and behaviours and heavily professional-led treatment may be counterproductive in the long term (Reid et al., 2008). Of course, advanced training on eating disorders addresses those issues. Perhaps HCP views of eating disorders patients as difficult and frustrating are partly caused by the large mismatch between ‘traditional’ paternalistic medicine and the needs of this patient group.

Staff also felt that services simply lacked the staff time to offer optimal treatment. As in previous research (Comerci & Greydanus, 1997; Hepworth, 1999; NICE, 2004; Ramjan, 2004), they recognised the importance of the therapeutic relationship and that ‘everyone was different’ and consequently felt frustrated at not always being able to work in sufficient depth with individual patients. On this point, 24hr residential

treatment does not necessarily mean protracted, regular psychological therapy. It does offer the potential for more interactions between patients and staff of all types and levels of expertise. All staff were interested in providing treatment and recognised the importance of the psychological component of treatment, so there is a need for services to develop more effective ways of using staff-patient contacts.

Finally, staff were well aware that even with specialist help eating disorders can take a long time to improve and can be relatively 'intractable'. There is an implicit need for long-term care planning, rather than working to a model where patients 'get better' and are therefore discharged entirely. Again, this suggests a need for primary care and different specialist services to work better together.

While this is a specific study of specialist staff in one UK city, the themes raised may well be relevant elsewhere in the UK and internationally. Informally and formally there is evidence that many areas in the UK lack specialist training and lack properly funded specialist services (Royal College of Psychiatrists, 2000). Eating disorder patients are diverse and complicated, so can require relatively protracted, individualised and intensive treatment of a type that does not necessarily fit well into the planning, budgeting or practices of existing service provision. In short, eating disorders patients are often considered difficult in part because their needs are more complex than can be met with relatively stretched and unskilled services.

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